



## **State of Connecticut**

### **HOUSE OF REPRESENTATIVES STATE CAPITOL**

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FINANCE, REVENUE AND BONDING COMMITTEE  
PUBLIC SAFETY AND SECURITY COMMITTEE

Testimony in Support of Proposed HB 6100

**An Act Designating Spinal Muscular Atrophy With Respiratory Distress Awareness Day.**

Government Administration and Elections Committee

February 25, 2015

Chairmen Cassano and Jutila, Ranking Members McLachlan and Smith, and members of the Government Administration and Elections Committee. I would like to thank the Committee for the opportunity to testify in support of Proposed **HB 6100 An Act Designating Spinal Muscular Atrophy With Respiratory Distress Awareness Day.**

Thank you for adding Proposed HB 6100 to today's public hearing agenda. I have a constituent who was born with SMARD, a rare and life-threatening motor neuron disorder. Hunter has over-come many challenges since he was born and has beaten the odds. His determination is inspiring and along with his family, Hunter will be sharing his story with you.

For further information on SMARD please visit the National Institutes of Health website at [www.nih.gov](http://www.nih.gov).

I respectfully ask that the Committee raise HB 6100 and welcome further discussions on a SMARD Awareness Day. Thank you for your consideration.

Sincerely,

Dave Yaccarino